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Self-Interested and Altruistic Motivations in Volunteering for Clinical Trials: A More Complex Relationship

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Abstract:

Empirical studies have found that altruism and self-interest are the two primary motivations for enrollment in clinical trials. Some studies have shown that in some cases these two motivations are contingent upon each other, which complicates our understanding of motivation. In this study we interviewed 27 people with Parkinson's disease about their willingness to enroll in a hypothetical clinical trial. Through inductive, grounded theory analysis of the interview transcripts, we find four different contingent relationships between altruism and self-interest. It is important for ethicists to be aware of these more complex motivations because some are ethically problematic and others not. Moreover, practitioners need to be aware of these contingent relationships so that they can understand the motivations of the research participants.

Self-Interested and Altruistic Motivations in Volunteering for Clinical Trials: A More Complex Relationship

Modern medicine is dependent upon the clinical trial, and "the primary goal of clinical research is to advance our understanding of health, illness and the treatment of disease for the benefit of society" (Truong, Weeks, Cook & Joffe, 2011, p. 616). Trials are often publicly justified by assuming altruism on the part of the participants. As Jansen writes, since the goal of the trial is to benefit society, not the individual participant, "those who seek to justify clinical research often point to the possibility that participants in clinical trials might have altruistic motives for participating. And for good reason. Altruistic motives can explain why rational people with full understanding would agree to participate in trials that offer little or no direct therapeutic benefit and expose them to significant risks of harm. Altruistic behavior, moreover, is virtuous" (Jansen, 2009, p. 26). There is also an extensive ethical debate on the extent to which altruism should be the motivation for participation in a clinical trial. On the one hand, altruism is a noble value. On the other hand, appeals to altruism can be seen as coercive and putting society's interests above those of the individual patient (Simon, Eder, Kodish & Siminoff, 2006, p. 40).

Despite the debate about the importance of altruistic behavior in justifying clinical trials, the extent to which altruism motivates volunteering

for trials is relatively unknown. Therefore, ethicists, social scientists and researchers have called for, in one scholar's words, "better data on the extent of altruistic motivation among research participants in a range of clinical trials" (Jansen, 2009, p. 35). Moreover, a deeper understanding is necessary as ethicists have called for medical researchers to question potential trial participants about their motivations to ensure they understand what a trial can and cannot do for them, and to insure they are giving truly informed consent (Kim et al., 2009, p. 13). To understand the potential trial participants' responses, clinical researchers also need a more developed social science of motivations for enrollment.

The existing empirical studies of people's motivations to enroll in trials generally show that individuals have both self-interested and altruistic motivations. Most studies treat the two motivations as independent, and assume that they are weighed to reach a decision of whether to join a trial. However, some recent research has shown that the motives are actually contingent on each other, which changes our assessment of both.

Contingent means occurring only if certain circumstances are in place. A simple example of a contingency is the statistical interaction effect which would occur when participants express stronger and stronger altruistic motivations as their stated self-interest increases. An example we will examine below is when altruism is contingent upon a certain level of safety (which is a type of self-interest).

Identifying contingencies is important because, if they exist, an ethical debate that presumes unitary or independent motives will not fit with empirical reality. It would then be important to develop a normative theory of contingent motivations. Moreover, if those conducting clinical trials try to ensure that the enrollees have proper motivations, a dependence on an incorrect theory based on unitary or independent motives will make accurate assessment difficult. Contingent motivation may be misidentified as either self-interest or altruism.

Therefore, to determine the actual roles of self-interest and altruism in justifications for trial enrollment, we need empiricists to be able to identify both their independent and contingent uses. In this paper we examine the stated motives for willingness to enroll in a trial of a stem cell (SC) treatment for Parkinson's disease (PD), and categorize the contingent relationships between self-interest and altruism when respondents state both motivations.

EMPIRICAL STUDIES OF SELF-INTEREST AND ALTRUISM IN TRIAL ENROLLMENT

There is a substantial literature on what motivates participants to enroll in clinical trials. The largest group of research studies have focused on concerns about "therapeutic misconception" (TM) which occurs, to take one of the more simple definitions, when the participant fails "to appreciate or understand that trial participation advances ends other than care" (Kimmelman, 2007, p. 40). In the terms of this paper, TM occurs when

participants do not understand that it is not necessarily in their self-interest to participate in a trial. A typical early research project on TM found that: “cancer patients who participate in phase I trials are strongly motivated by the hope of therapeutic benefit. Altruistic feelings appear to have a limited and inconsequential role in motivating patients to participate in these trials” (Daugherty et al., 1995, p. 1062).

In the later years of research on TM, it became apparent that while some participants do not understand that trials are not treatment, it is often the case that when enrollees say that they hope that the trial gives them a medical benefit, it is not that they are misinformed about the purpose of a trial (Kim et al., 2009). Rather, they are often desperate and are hoping for the remote possibility of receiving medical benefit (Christofides, Stroud, Tullis & O'Doherty, 2017), or for any number of positive psychological functions that hope serves (Sulmasy et al., 2010). In light of these developments, scholars now make a distinction between true TM, which is apparently more rare, and “therapeutic optimism,” where “prospective participants and actual research subjects understand the likelihood of benefit but hope they will personally benefit from participation” (Sisk & Kodish, 2018, p. 14).

There is now a more general literature on enrollee motivations, which consistently shows that there are two main motivations for enrolling in a trial: altruism and the hope for self-benefit, however remote or diffuse. The

vast majority of the literature treats these as independent motives. For example, one summary of this literature:

> found ten studies . . . where altruistic motivations were reported, and 13 which reported self-interested motivations. Ten of these studies reported on both types of motivation; in just half of these the percentage of patients citing altruistic reasons was greater than that citing personal benefit. The review authors noted that it is not always possible to identify which motivation is the primary motivating factor. For example, [one study] reported 74% of people gave non-altruistic reasons and 65% altruistic, but participants expressed more than one motivation and there is no indication which people thought was most important (Locock & Smith, 2011, p. 86).

Another study found that while "approximately half of respondents identified altruism as a very important motivation, less than 1 in 7 reported that altruism was their primary reason for joining the trial" (Truong et al., 2011, p. 622).

Studies of self-interest and altruism in other areas also suggest that these motivations are not unitary or independent. For example, studies of psychological motivations for financial donations have shown a combination of these two motives (Feiler, Tost & Grant, 2012). Therefore, it is likely that in the case of clinical trials these motivations are not independent, but rather contingent upon each other.

A few studies have examined contingencies between self-interest and altruism in participation in clinical trials. These have been described in a meta-analysis of qualitative research studies of participants' motivations by McCann and her colleagues as "conditional altruism" (McCann, Campbell & Entwistle, 2013). We start by demarcating two distinct contingencies that McCann and colleagues place together. First, they see altruism as conditional on the expectation of benefit to the participant, such as in their own empirical study that finds that altruism motivates people to enroll in a trial, but does not lead to participation in practice unless they see participation as helping them personally (McCann, Campbell & Entwistle, 2010, p. 1). Similarly, Canvin and Jacoby find that altruism is conditional on the trial being "potentially beneficial or unlikely to be harmful" (Canvin & Jacoby, 2006, p. 1). We will call this altruism contingent on benefit.

McCann and colleagues also consider it to be a case of conditional altruism when altruism is conditional on avoiding harm to oneself. For example, one study of a pre-term labor clinical trial finds that the first motivation for participation was "the possibility of an improved outcome for the baby. The second and less prominent motivation was the opportunity to help others, but this was conditional on there being no risks associated with trial participation." (Kenyon, Dixon-Woods, Jackson, Windridge & Pitchforth, 2006, p. 98). We call this altruism contingent on avoiding harm.

While McCann and colleagues combine these two contingencies, we separate them because they may have different ethical evaluations. In the ethics of clinical trials, altruism does not require that people risk their lives – it does not require supererogation (Jansen, 2009, p. 27). Granted, there is no agreed upon threshold of risk one would take for altruism, but one could still be an altruistic person and not join a trial with a 50% chance of mortality.

Therefore, altruism contingent on avoiding harm should not be as worrisome to ethicists as altruism contingent on benefit. The altruism contingent on benefit and altruism contingent on avoiding harm identified by McCann and colleagues go a long way toward a more complete understanding of the relationship between self-interested and altruistic motives. However, in our research we find two other contingent relationships between self-interest and altruism in our data: altruism contingent on the trial not being in their self-interest and altruism contingent on depleted self-interest. These findings will help advance our understanding of individuals' nuanced motivations for participation, improve researchers' design of clinical trial protocols, and clarify ethicists' assessments of clinical trials.

METHOD

These data are from a larger project on the views of people with Parkinson's Disease (PD) toward stem cells (SCs) and clinical trials using SCs. Between January and December of 2018 we recruited respondents for in-

depth interviews from four sources: the patients of one of the largest medical practices that treats Parkinson's disease in the region; a local Parkinson's association web site; boxing gyms with special sessions for those with Parkinson's; and four Parkinson's support groups in Southern California. These would be the populations from which a phase I clinical trial would recruit. We obtained one interview from the doctor's office, zero from the boxing gyms, two from the association website, and the remaining 24 from the support groups. This research was approved by the Human Research Protections Program of the corresponding author's university, project #172081.

Respondents were told we were interested in talking about their attitudes toward and understanding of SC clinical trials and they signed a written informed consent form. In sum, we conducted 27 face-to-face interviews that averaged 62 minutes in length, with a minimum of 35 and a maximum of 103. (For the interview guide, see Appendix A.) Respondents were all white except two Asian Americans, and 30 percent were women. While one respondent did not state their age, 15% were in their 50s, 37% in their 60s, 30% in their 70s and 15% in their 80s – as would be expected in a population of PD sufferers. All respondents lived in California.

The sample is likely overly exposed to what scientists say is the purpose of a clinical trial. This is because more education likely means more exposure to science (Evans, 2011, p. 720), and the sample is very well

educated: 19% had a high school degree, 29% an undergraduate degree, 41% a professional degree or more (11% did not state their education level). Given that most of the interviewees were part of a support group, they are probably more aware of PD research and scientific research in general, than the average person with PD.

For the interviews we used a fixed interview guide but with open-ended follow-ups to each question so as to ensure we understood each respondent's views. All of the interviews were transcribed except one, where the respondent did not want to be recorded. The responses were inductively coded using the NVivo software package, and the resulting categories were discussed by the three authors and subsequently modified.

To examine motivation for participation in a trial, we asked four questions in sequence that we analyze together. The first question was: "can you explain what an early phase clinical trial is?" The second was: "would you sign up for an early phase clinical trial?" The third question tried to remove TM from consideration and emulate what they would be told when enrolling, by reminding them that the trial is not designed to help them. We asked: "Would you sign up for a trial that is not designed to help you?" The fourth question was to identify strong altruists, were they to exist in the sample. The question asked: "Would you sign up for a trial that is not designed to help you, and which could potentially harm you?" In analyzing the respondents' answers to these questions we inductively generated

several types of motivation to participate in a clinical trial, which we enumerate in the Results section below.

RESULTS

We categorized all of the respondents into seven mutually exclusive categories. In Table 1 we summarize the categories of respondents who treat altruism and self-interest as independent, as well as the four contingent relationship categories. We find that roughly a third of the respondents have either altruistic motivations, self-interested motivations, or both motivations (but without the motivations being contingent upon each other). About two thirds have one of the four contingent relationships between altruism and self-interest, suggesting that contingency may be the dominant phenomena in motivations for participating in clinical trials.

Insert Table 1 Here

Only Self-Interest

We start with self-interest. Consistent with other studies, there is about a fourth of the sample who do not volunteer altruism as a motivation, even after the questions turn to saying that the trial is not designed to help them, which should prompt altruistic motivations, if they have them. The benefit they see from the trial is a long-shot gamble that somehow the trial

would help them, given that they have no other options. Many explicitly rejected altruism.

For example, R20 says in response to the trial, “Yeah, I might give it a go” because “What do you have to lose? . . . I’ve tried five or six medications; I couldn't take any of them.” When asked his motivations, he said “Some kind of help. You know, help with symptoms, help with day to day living.” We continued with the next question, asking if he would sign up for a trial not designed to help him, and he said “Not really, I don't see the point. . . . You know, it doesn't make any sense to me. Why sign up for something that's not going to benefit me?” Similarly, R6, right after correctly noting that the goal of an early phase clinical trial is “to see if it’s safe,” states that to enroll he would “need to consider what the potential was of getting some relief. . . . I’m pretty desperate to get back to my old life.” He was not interested in any trial that would not benefit him or would potentially harm him.

A variant of this self-interested motivation is that they would consider enrolling in the future when they are desperate enough and out of treatments. R12 says they would not enroll, “at this point in time.” He says that “I’m at the early stages of Parkinson’s, and so, my quality of my life is not yet impaired that I need to be a subject of risk. . . . it’s not that I’m afraid of something new, it’s – it’s a sensible balance of the risk versus reward.”

In case his motivation of self-interest was not clear, we asked the next question in the sequence, which was “would you sign up for a trial that was not designed to help you?” to which he replied “That sounds like an even worse.” He later said “I’m all for helping science. But not at risk to me.” At our final question he clarifies his motives, saying he would consider participation when he has “exhausted, you know, reasonably standard and well-proven therapies.” It is important to note that within this category, at no point did these respondents indicate that they would be motivated to participate in a trial for altruistic reasons; even in their desperation, they were motivated by hope for self-interest.

Only Altruism

There was only one respondent who had a strong – but not perfect – supererogatory form of altruism, and is explicitly willing to put himself at risk for science. Note that R2 was particularly knowledgeable about clinical trials – so knowledgeable that he may be repeating the assumed norms of these trials. He responded to our first question that he would participate in these trials “because I think I have an obligation to do whatever I can to help the future generations of people dealing with a disease of any kind. . . . I think we have a moral obligation to help humanity.” He would participate in a trial not designed to help him because “None of the trials are designed to help you. . . . that’s the way it works.” When we got to our most stringent question – whether he would participate in trial that could hurt him, he said

“I would evaluate the risks. If I felt that the researchers involved, the clinicians involved, the institution involved were all reputable I would consider it, yes.” This person is important because he shows that the near-pure altruism is possible but rare.

Both Self-Interest and Altruism

The primary literature on enrollee motivations describes enrollees as having both self-interested and altruistic motivations, and the literature assumes that enrollees weigh these two factors when deciding whether to enroll in a trial. For example, McCann and colleagues describe this as “weighing up” the two motivations (McCann et al., 2013, p. 234). In the research literature, the two motives are not contingent on each other. While it is possible that we could have revealed a relationship with further questioning, there were only two respondents who stated both motivations without making them somehow contingent on the other.

For example, R15 said he would participate in an early phase clinical trial “depending on the circumstances” because “One it might work. Two it might help somebody else down the road, which is the more likely situation.” Note how these are discursively separated. After the question about joining a trial not designed to help him, he continued with equally weighing both motives saying the reason for enrolling would be the “two reasons I mentioned before; it might work and it might help somebody else.” Like the

scales of justice, with this type of dual-motivation, a person is conceptualizing altruism and self-interest as two separate entities, and weighing their respective merits as they decide.

Altruism Contingent on Avoiding Harm

Ethicists should note that all but one of the respondents who mentioned altruism as a motivation made it contingent in some way on self-interest. However, we begin with altruism contingent on avoiding harm, a type of self-interest, which was identified by McCann and colleagues. This motivation is not ethically problematic. Respondents often started by mentioning altruism, with no mention of individual benefit, but had safety limits to their altruism when we got to the question about a trial that would cause harm. For example, R23 explains his motivation by saying “the fireman knows his risk because he's educated in it. He weighs those chances before he goes in. If you're going to save a life don't put your own life in that much danger; because then you can't help the person. You're no help at all if you're dead.”

Similarly, R19, after articulating that the point of an early phase trial is to look for “adverse reactions,” said he would participate because having followed the research “there’s a potential for good things to happen.” He also said that “I think there’s potential to cure some really bad diseases,”

which indicates he is thinking of medical treatments in general, not for his particular disease.

When asked if he would sign up for a trial not designed to help him, he said “if there was limited damage . . . But if the potential is there to really help people, other people, yeah.” He further articulated the social basis of altruism when he noted that the medicine he currently uses would not exist without others’ altruism: “there’s a lot of people already done trials for the stuff that I’m doing right now.” But, he said he would “probably not” participate in a trial that may harm him because “Nobody wants to be hurt. Nobody – nobody wants to do damage to themselves.”

R7 would participate “as long as it was transparent” about risks because “I feel that if it was something I had to give then I could be of value. . . . to the process of finding a treatment . . . for everybody.” But, on the trial that could possibly harm him, he said “quite possibly not” because “to deliberately put myself in harm’s way” does no good.

Finally, R23 would consider enrolling in trials not designed to help him, depending on risk, because “you wanted to help some people.” He concludes that “As long as the adverse effects are not lasting, permanent harm then I would do it. But I'm not going to commit suicide. I like life too much.”

Altruism Contingent on Benefit

The second contingency relation between altruism and self-interest identified by McCann and colleagues is altruism contingent on benefit. The ethical relevance of this category is that it suggests that altruism is not actually operative as a motive for enrollment as it is for altruism contingent on avoiding harm, because an initial statement of an ideal of altruism is contingent on the inverse of altruism – that the trial will give them some personal benefit.

However, this combination is rare in our data, with only two respondents in this category. R1 says they would sign up for an early phase clinical trial because "Well you got to have bodies you got to have people in the trials, or you don't have enough evidence if you don't have enough people in it. So the more people you can get into it the more likely you are to discover something." This altruistic motive changes when asked whether he would sign up for a trial not designed to help him, to which he answers "probably not." He would need to be convinced that he would "have symptomatic relief; I have actual relief. . . . So you got to make me believe that there's some benefit, or that it won't cut me short."

Similarly, R14 gives both self-interested and altruistic reasons when considering the clinical trial question, saying they would probably enroll "because I would be very selfish in wanting to see whether or not I could benefit from something like that, and the second reason would be you would need subjects to be involved in studies in order to find solutions to the

future. . . . without people to volunteer to be involved in clinical studies, they can't move forward then proving that something works." When asked if they would sign up for a trial that wasn't designed to help them, they said "Probably not, just no. If it doesn't have any benefit for me, I don't think so because . . . clinical trials take a lot of time and I don't think that I have, and that optimistic to participate in something that I won't have any kind of benefit from it." As for the trial that could possibly harm them, the answer is "definitely not:" "why would anyone sign up for a clinical study if they won't, if it potentially won't benefit them? I can't see why anyone would do that."

Altruism Contingent on the Trial Not Being in their Self-Interest

Besides separating the contingencies identified by McCann and her colleagues, we inductively identify two more in the data. The first of these is altruism contingent on the trial not being in their self-interest. In his study of acts of compassion, Wuthnow finds that Americans lack a language to justify acts of caring or altruism, so they give self-interested motivations for their altruistic acts (Wuthnow, 1991). The acts themselves may be altruistic, they just cannot justify them as such. We see this in a category of respondents who initially express self-interested motivations. But, upon hearing that the trial is not designed to help them, they then offer altruistic motivations. These people may be common in empirical studies of motivations for enrolling in clinical trials, but their ultimate altruistic perspective may be

hidden by their initial statement of self-interest. They can be recognized by the direction of their shifting accounts of their motives.

For example, R24, after describing early stage clinical trials as “risky” with “dangers,” says he would not sign up for such a trial because he is not yet desperate enough to need untested treatments: “because I'm limping along pretty good here. I mean if I was further down the line I might do it. And I'm not that brave maybe.” When asked about a trial not designed to help him, he said no, “Unless there was some tremendous benefit to everybody I might do it. But I think I'd be very cautious about it.”

R16 would sign up for an early-phase clinical trial “Because if it works – if it works, it’s great.” This suggests a self-interested motive. When asked if he would sign up for a trial that might not help him, he said “you never know if a trial is gonna help you or not, so it doesn’t matter. Anything I’m worth trying, I understand what we’re all about. I’m not selfish.” He concludes after saying that he might participate in a trial that could harm him that if it doesn’t help him, then “the research on me helped somebody else, great. That would be a great thing. It’s an awful disease. I wouldn’t wanna wish it on anybody.” R9 says he might sign up for a trial because “It would provide hope for getting better.” When asked about a trial not designed to help you, his altruism emerges when he says he would do it “because I have love for all mankind” and that it “might help somebody else, yes.”

Relatedly, others initially express both self-interest and altruism, but when told that a trial is not designed to help them, retain the altruism. R11 would enroll because "obviously I want to be helped and cured of my own disease but also I want to be able to participate in helping others with their suffering and their struggles as well more than myself. There's many people that are suffering from this disease and I want to be part of the healing process if I can be." After the question that clarifies that a trial would not be designed to help him he said "if the benefit was to help others but would not help me, I would participate in that. Again one of my goals is to help others. Not just myself."

R22 is interested in the trial for two reasons: "Number one to get better. Number two, I really think it's my responsibility to further generations and to people who aren't diagnosed yet to get help to find this out. I mean they've got to do it on somebody, and you know, I would always look and see, do my research and find out what I could and just balance the risk versus benefits that yeah, I definitely would be up for it." When asked about the trial not designed to help him, he said he would "absolutely" sign-up because I "kind of think the responsibility is to help each other out."

Altruism is the main motive here, even though it would appear that self-interest is because they mention it first. If self-interest were the dominant motive, they would have said at the second question that they

were not interested, like those in our “self-interested” category did. Altruism acts as the unstated dominant motive.

Altruism Contingent on Depleted Self-Interest

A final contingency will be well-recognized by those who run phase I clinical trials, but it is important to recognize that it is another contingent relationship between self-interest and altruism. For some, altruism is contingent upon reaching a point in their disease where they have no more self-interest. R26, after describing the purpose of an early phase clinical trial of “seeing if it is deadly,” said he would sign up for a trial once he was out of other options for treatment. He said that if the deep brain stimulation and other medications “leave me hanging in the emergency room, I would jump all over it.” In case that was not clear that he was motivated by having no other options, he said if he were in that situation “it would be well worth the risk to try the whole head transplant. I would try.” His contingent altruism emerges when we asked if he would sign up for a trial not designed to help him. He first asked, “Well, who would it help?” to which the interviewer responded “Maybe people down the line,” and he said “Yeah if I was if I knew the rest of my life was crap I would consider it.”

Similarly, when asked whether he would participate in a trial, R18 says “Maybe not. There is no need. I am not that nice. Unless I am half dead or dying anyway and then I would be fine with it. . . . then I'd be like, well,

what's, you know what's the harm? But at this point I am not ready to risk getting sicker with some other random disease." He would not at present sign up for a trial that could harm him. At present he is not altruistic but self-interested. In a few years, however he may be altruistic because he will have no more self-interest.

R5 would participate because "it might help find a cure for whatever it is they're studying, . . . with Parkinson's I'd participate whether there was any compensation or not. I think it would be great if they found a cure for this." He continued by saying "I hope I can contribute to the research that will eventually find a cure. I hope, but it's sort of a distant hope. I'm 80 years old. I'm going to die of something else before too long. But if I could contribute to – it's like [being an] organ donor." This group is important ethically because it categorizes the well-recognized phenomena of people volunteering for trials when they are going to soon die of their disease; it is also distinct from those who are desperate but still only motivated by self-interest.

DISCUSSION AND CONCLUSION

In this paper we examine the stated motivations of people with PD for enrolling in a clinical trial. Like the empirical literature on enrollee motivations, we find a group that is purely motivated by the self-interest that the trial could possibly benefit their health, even though it is not designed to

do so. We also find one person who is motivated by an almost supererogatory version of altruism. While most of the literature finds people with both motivations of self-interest and altruism that are independent of each other, we only find a few in that category.

More importantly, about two-thirds of the sample had one of four different contingent relationships between altruism and self-interest. A large group stated altruism contingent on avoiding self-harm. While all trials involve some risk, it is not surprising – and not ethically problematic – that people want to avoid harming themselves during their acts of altruism.

The least prominent was the altruism contingent on benefit focused upon by McCann and colleagues where people initially assert altruism, but when they realize that the trial will not help them, are no longer interested in enrollment. We also found what we call altruism contingent on the trial not being in their self interest. This is where respondents initially appear to be self-interested, but when disabused of that the trial is in their interest, begin to assert altruism as a motive. For the ethics of clinical trials, altruism remains the driver here, because trials are not supposed to be in the enrollee's self-interest.

The final contingency was found in respondents who shift between self-interest and altruism as they progress in their disease. They become altruistic when they no longer have self-interest because of how advanced their disease is. While this motivation is well known among medical

researchers, it is important to identify it as a mixture of self-interest and altruism so that these mixtures can be properly theorized in the ethics of clinical trials.

These categories should be kept in mind when trying to assess the relative prevalence of self-interest and altruism in clinical trials. In our sample, only a minority expressed only self-interest. The strong majority had altruism as a motive, but almost always in a complicated contingent relationship with self-interest. Our work thus advances a typology of motivations for participation and identifies two new contingencies in the relationship between altruism and self-interest.

BEST PRACTICES

These results are important for clinical researchers who are being called upon to determine the motivations of potential trial participants. For example, Kim and his colleagues suggest a conversation quite like our interviews: “Mr. Jones, now that we’ve had a chance to review the study in detail, it would be helpful for me to know what you are hoping for by participating in this study. Can you tell me in your own words why you would like to participate?” Their hope is that researchers can determine “whether the individual clearly understands the purpose and nature of the study but is truly an altruist, or an optimistic gambler (whose statements about expectations of benefit are not misconceptions but perhaps reflect a need to

maintain a hopeful outlook)" (Kim et al., 2009, p. 13). As medical researchers develop means of determining what people's motives actually are, it is important to take into account the complicated and contingent relationship found in people's stated motives that we identify in this paper. If the results of this paper are generalizable we would expect, for example, that altruism will be pervasive, albeit difficult to see as it is contingent in various ways upon self-interest.

The ethical grounding of clinical trials is an ongoing concern, and it is important that normative ethicists be aware of people's actual motivations for enrollment in trials. Ethical justifications of trials should incorporate the best empirical data available, and this paper reveals the complexity of people's motivations.

RESEARCH AGENDA

This study has a number of obvious limitations. The respondents are only from one disease-group in one geographic area with a trial that is hypothetical. The sample is disproportionately educated and predominantly white. That said, such compromises are required for an in-depth interview study.

This study is also limited in its examination of self-interest because the questions we asked were geared largely toward medical benefits and harm. A more complete study would find a way to evaluate a more expansive set of

potential self-interests such as increased social integration or improved psychological health.

To determine whether the findings in this paper are generalizable, scholars need to conduct research on different populations in the U.S. and the world and for different types of clinical trials for different diseases. Researchers need to use different interview questions to ensure that the finding replicates with other ways of measuring enrollee motivation. Moreover, research needs to be conducted among people who have actually enrolled in a clinical trial. Finally, quantitative researchers could examine whether contingencies, operationalized as interaction effects, exist in their data.

EDUCATIONAL IMPLICATIONS

The findings suggest that people's motivation for enrolling in clinical trials are even more complicated than previously thought. Therefore, the training of clinical trial managers should account for these complexities so that practitioners are properly understanding enrollee motivations. Those learning about the ethical basis of research on human participants should be taught about the complexity of motivations.

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